



Evaluating Knowledge of Autonomic Dysreflexia Among Individuals With Spinal Cord Injury and Their Families

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Abstract

Background/Objective: Autonomic dysreflexia (AD) is a potentially life-threatening complication of spinal cord injury (SCI) characterized by episodic paroxysmal hypertension and bradycardia in response to a noxious stimulus below the level of injury. Recognition of AD is crucial for individuals with SCI and their family members to facilitate timely and appropriate management. The objectives of this study were to (a) evaluate knowledge of AD among SCI consumers and their family members and (b) identify the preferred format and timing of education regarding AD recognition and management for these stakeholders.

Methods: Cross-sectional descriptive study on a cohort of community-dwelling individuals with chronic SCI (N = 100) and their family members (N = 16) by self-report mail survey. Frequency distributions were used to tabulate survey responses on AD knowledge level and to characterize learning preferences and $2 \times 2 \chi^2$ analyses were conducted to determine whether there were factors (ie, impairment) associated with AD knowledge (ie, how to treat AD).

Results: Individuals with SCI and their family members have gaps in their knowledge of AD. Traumatic SCI etiology (vs nontrauma) was associated with greater knowledge about treating AD. Although the SCI sample was a high-risk group, 41% had not heard of AD. More concerning was that 22% of individuals with SCI reported symptoms consistent with unrecognized AD. Respondents indicated that AD education would be best delivered during rehabilitation by a healthcare professional.

Conclusions: Further work is needed to promote knowledge about recognizing and managing AD. This may help reduce risk of cardiac and cerebrovascular disease in the SCI population.

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INTRODUCTION

Although the loss of motor, sensory, and autonomic function is a devastating consequence of a spinal cord injury (SCI), the number of secondary health complications associated with the SCI can have equally detrimental effects on health status (1,2). In particular, autonomic dysreflexia (AD) is a potentially but often unrecognized life-threatening condition that requires immediate attention. AD is an acute syndrome characterized by paroxysmal hypertensive episodes and is frequently combined with signs and symptoms such as pounding

headache, slowed heart rate, and upper body flushing (3–7). AD increases with the level and severity of injury (8,9). Hypertensive crises in AD can be life threatening and result in seizures (10–14), recurrent cardiac arrest (13), retinal or subarachnoid hemorrhages (11,15), stroke (6,11,15–17), and death (6,11). Like chronic hypertension, AD can lead to cardiovascular damage. Disordered cardiac control and or subclinical AD may account for the prevalence of asymptomatic coronary artery disease after SCI (18). All persons with SCI may have an elevated risk of asymptomatic coronary artery disease, but the risk may be highest among patients with lesions above T6. Although AD is highly prevalent (~90%) in persons with cervical or high thoracic SCI above the splanchnic outflow (19–22), the pathophysiology of this potentially lethal condition remains poorly understood (4,23). Despite the presence of published guidelines for the recognition and management of AD

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(24,25) for healthcare professionals and patients, the current literature regarding consumers' (patients and their families) or health care providers' (physicians, nurses, etc) knowledge of AD symptoms and management is poorly described (26).

Prevalence of asymptomatic cardiovascular disease for those aging with SCI is 60% to 70% (27,28). The potential exacerbating impact of AD makes knowledge transfer concerning AD a priority for consumers and healthcare providers (29). The prevention, recognition, and effective management of mild to severe AD may ultimately reduce the risk of cardiac and cerebrovascular disease in the SCI population. AD can be quickly treated and reversed by consumers themselves, family members, or pre-hospital providers (30). In most cases, the prompt emptying of a patient's bladder and/or bowels will resolve most AD episodes, although other precipitants may not be addressed in the pre-hospital setting. In these situations, consumers may need to be transferred to a Level I trauma center for monitoring and administration of antihypertensive medications (5,30).

One possible tool to aid Emergency Medical Services workers and other healthcare providers to recognize an episode of AD is an information card (wallet-sized) that a person with SCI can carry (31). For wallet cards to be effective, however, the consumer with AD needs to recognize that he or she is having an episode of AD. Currently, there is work to provide an AD protocol to telehealth services (32), but AD episodes are not always apparent, especially in cases of silent dysreflexia (33–35).

Given the pathophysiology of AD and the spectrum of signs and symptoms, further understanding of this condition may be achieved through consultation with consumers, providers, and scientists. A first step in this collaborative process is to ascertain the current state of knowledge regarding AD among various stakeholders. To date, there have been no publications assessing consumer knowledge about AD recognition. There is a tremendous amount of education these patients must absorb to try to cope with their situation and to adapt to their environment (36). One of the largest problems facing patients with SCI is coping with the changes in their quality of life after their injury (36). As such, the likelihood of AD education being forgotten or inadequately emphasized during the rehabilitation process is high, which may contribute to poor recognition of the symptoms and understanding of the consequences of AD. Considering the impact AD has on a patient's health, identifying gaps in knowledge is crucial to prevent occurrences of AD and facilitate early recognition and emergent assessment.

We postulated that individuals at risk for development of AD based on neurologic level of injury and their family members may not have sufficient knowledge of AD symptoms to recognize AD episode(s). Although patients or family members may be aware of the critical form of AD, they may not be aware of the more subtle forms of AD or of its implications on long-term health.

Thus, the purpose of this study was to evaluate knowledge about AD among consumers with SCI and their family members' with the larger goal of providing key stakeholders with the necessary life-saving tools to recognize AD and facilitate access to appropriate AD management. Specifically, we aimed to (a) evaluate knowledge of AD among SCI consumers and their family members and (b) to identify the preferred format and timing of education on AD for these stakeholders.

METHODS

Measures

Two separate questionnaires were developed for consumers and their family members regarding AD knowledge. The questionnaires were modified from a quality improvement study that evaluated knowledge of AD as presented in the current Paralyzed Veterans of America (PVA) guidelines for recognizing and managing of AD (26). The questionnaires were designed in-house by a team of physiatrists and psychosocial researchers with the intent to probe knowledge of AD. The questionnaires contained a variety of open-ended items, symptom checklists, and Likert rating scales. The questionnaires were tested for content validity and readability by the investigators. In addition, the questionnaire was piloted on 3 consumers with SCI who worked as research assistants (ranging from 1 to 5 years) in our department to obtain feedback on its design, language, and administrative burden. All 3 had an undergraduate degree, and 1 was a master's student in a rehabilitation science program.

Consumer Questionnaire

The consumer questionnaire consisted of 74 questions that collected information on (a) demographics and injury characteristics (eg, level, completeness); (b) secondary health complications related to AD; (c) general knowledge of AD; (d) personal experience with AD (if applicable); (e) perceived importance of learning about AD and other SCI topics; and (f) consumer's perceptions on when AD education should be delivered (eg, acute care, rehab, community).

Family Member Questionnaire

The family member questionnaire was designed to accommodate the perspectives of partners, siblings, parents, and friends of consumers with SCI. The questionnaire was made up of 13 questions regarding (a) demographics; (b) knowledge of AD; (c) how AD knowledge should be distributed to family members; (d) family member's perceived importance of AD; and (e) family member's perceptions of when consumers with SCI should learn about AD.

Procedure

The sample was identified through the health records department of a tertiary SCI Rehabilitation Center.

Contact information was selected for persons who were former patients and who had a neurologic level of T6 or above. Questionnaires for consumers (n = 450) were mailed out with an accompanying letter explaining the study purpose and a stamped return envelope. When the questionnaires were returned marked "return to sender," contact information was cross-referenced through health records (some records contained >1 mailing address) and questionnaires were resent to the potential participants' current address. Consumer survey respondents who consented to be contacted were called by a research assistant by telephone requesting a mailing address for family member contact information. A full explanation was provided for the reason for requesting family member contact. After obtaining consent, 23 family member surveys were mailed out. Reminder postcards were mailed out 3 to 4 weeks after the initial mail-out in attempt to increase the number of questionnaire respondents.

Once returned, impairment (level and completeness) was verified with health records for those respondents who did not know the specific details of their injury. All of the questionnaire responses were handled anonymously using a unique 3-digit identifier. The last page of each questionnaire asked participants if they could be contacted again regarding the study and provided a space for their contact information. These contact pages did not contain the unique identifier and were detached from the questionnaire to maintain the anonymity of all the participants. All applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research ethics board approved study.

Statistical Analysis

All the data from each questionnaire were entered into a customized SPSS database. Descriptive statistics including frequency distributions and percentages were used to tabulate responses to determine consumer and family member knowledge of AD, to provide an indication of severity and frequency of AD episodes, and to illustrate preferred formats for knowledge transfer of AD. As well, $2 \times 2 \chi^2$ analyses were conducted to evaluate whether there was an association between knowledge on AD and blood pressure with the following variables: (a) level of injury (tetraplegia vs paraplegia); (b) completeness of injury (complete vs incomplete); (c) etiology (trauma vs nontrauma); and (d) level of education (<postsecondary vs >postsecondary). In cases where the expected counts were <5, the Fisher exact test was used to test for associations between variables instead of χ^2 . The α level was set at 0.05.

The SCI consumer sample (N = 100) was divided into 4 subsets for the purpose of analysis: (a) participants who self-reported having knowledge of AD (n = 59); (b) participants who self-reported having no knowledge of AD (n = 41); and (c) participants with prior AD episodes

(n = 37). Finally, the questionnaires from participants who reported no prior episodes of AD (n = 63) were screened to ascertain whether they reported unrecognized episodes of AD. This was determined by taking into account their level of impairment, and their responses on blood pressure information (if any), and signs and symptoms reported during health complications and/or medical tests. Review of responses was conducted by a physiatrist (CM) with more than 15 years of experience working in the SCI field. After completing the review, 22 participants were identified as having possible episodes of unrecognized AD.

RESULTS

Consumers With SCI (N = 100)

Four hundred fifty patients were identified through the health records department at Toronto Rehab's Spinal Cord Rehabilitation Program. One hundred eligible individuals (71% men and 29% women) with chronic SCI responded to the mailed questionnaires for a response rate of 22%. Mean age of respondents was 53.6 years (SD = 16.9 years), and mean duration of years postinjury (YPI) was 8.9 years (SD = 9.9 years). The majority of participants had tetraplegia (79%) with incomplete injuries (48%), and those with paraplegia (21%) had incomplete injuries (11%). Trauma (ie, motor vehicle accident, sport injury, fall) was the most frequent etiology of SCI (78%). Most of the sample (77%) reported being unemployed or retired, and the rest (23%) were either employed (full- or part-time), were students, or were volunteers. With regard to education, 58% reported having a high school diploma or less, and 42% had a postsecondary degree (ie, university or college degree, technical school).

Health Status and Blood Pressure Management

All participants (N = 100) were asked whether they had experienced secondary health complications known to be triggers of AD in the past year (Figure 1). Overall, 68.7% reported having a bladder problem (eg, infection, incontinence, stones), 34.6% reported having a pressure ulcer, 67.4% had bowel problems (eg, constipation, incontinence, hemorrhoids), 20.5% reported having an ingrown nail, and 71.6% reported having pain in some part of their body.

Some respondents indicated more than 1 response for questions on blood pressure (BP) management. When asked about their BP monitoring practices (n = 90), 42% of consumers reported that their BP was measured every time they visited their family physician, 19% measured their BP when not feeling well, and 19% reported monthly BP assessment. Only 10% of consumers measured their BP on a regular basis (eg, daily, weekly).

Participants were asked to select 1 of 4 categorical responses (ie, low, normal, high, do not know) regarding their BP. Of 98 respondents, 51% reported having normal BP, and 33% reported having low BP. Very few

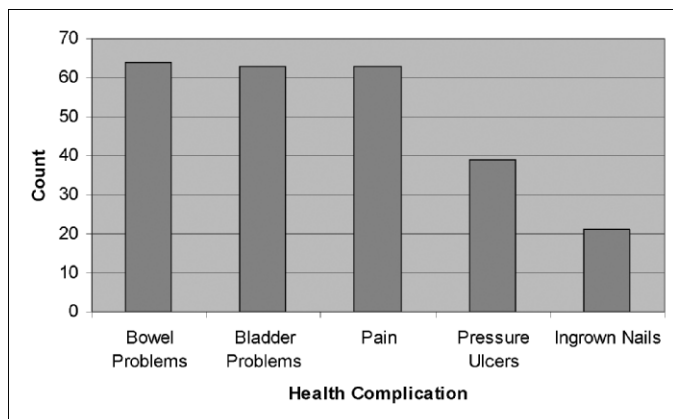


Figure 1. Frequency of the secondary health complications among responders ($N = 100$). Presence of the condition was calculated by summing the responses “Always,” “Very Often,” and “Sometimes” included in the questionnaire.

respondents reported having high BP (7%), and 10% of the sample did not know if they had high or low BP. When asked to report their actual BP (mmHg), most consumers did not know what their BP values were while lying down or when seated. Only 19% of respondents knew their usual heart rate.

AD Knowledge Among Consumers

Some respondents indicated more than one response for questions on AD knowledge. When asked about their knowledge of AD, the majority of participants (41%)

reported never hearing about AD, 29% clearly remembered that AD was mentioned as a possible complication after SCI, 25% had an individual and/or group education on AD causes and management during rehabilitation, 18% reported vague recall that AD was mentioned during their hospitalization, and 3% did not respond.

Those who had heard of AD (ie, vaguely, group education, clearly remember) were collapsed into a single group ($n = 59$). If consumers had never heard of AD ($n = 41$), they were asked to not respond to the section of the questionnaire that assessed AD knowledge. It should be noted that the group who had heard of AD was significantly younger than the group who had never heard of AD [$t(98) = -4.771$, $P < 0.001$]. However, there were no significant differences with regard to their mean YPI [$t(98) = 0.876$, $P = 0.383$]. Table 1 shows the demographic and impairment characteristics of these subsets.

Knowledge of AD. A significant portion of respondents ($n = 59$) had experienced and/or knew about AD. When asked about changes in BP during episodes of AD, 58% (34/59) of the subsample correctly reported that it was characterized by an increase in BP. Some of the most common triggers for AD indicated by respondents were bladder infections (73%), constipation (69%), tight clothing/devices (61%), ingrown nails (34%), and pressure sores (31%). Other triggers reported by consumers included spasticity (24%), high/low temperatures (25%), and menstrual cramps (20%).

Subset respondents (63%) were aware that untreated episode of AD could lead to death. Few reported not

Table 1. Demographic and Impairment Characteristics of AD Subsets

	Knowledge ($n = 59$)	Knowledge + AD ($n = 37$)	No Knowledge ($n = 41$)	No Knowledge + AD ($n = 22$)
Sex				
Men	43	29	28	9
Women	16	8	13	13
Age (y) [mean (SD)]	47.5 (15.4)	42.3 (13.9)	62.4 (15.1)	55.3 (11.8)
Years post-SCI [mean (SD)]	9.6 (9.8)	12.5 (11.4)	7.9 (10.1)	10.8 (11.8)
Impairment				
Incomplete tetraplegia	28	13	20	10
Complete tetraplegia	23	23	8	1
Incomplete paraplegia	3	—	8	6
Complete paraplegia	5	1	5	5
Etiology				
Traumatic	54	36	24	15
Nontraumatic	5	1	17	7
Employment				
Working	13	9	9	7
Not working	44	28	32	15
Level of Education				
>Postsecondary	31	20	27	13
<Postsecondary	26	17	13	7

Table 2. Symptoms and Associated Precipitant of AD Episodes Reported by Subset With Possible Unrecognized AD (n = 22)

AD Symptoms*	Precipitant							
	Bladder Difficulties (n = 17)	Bowel Difficulties (n = 18)	Bowel Routine (n = 22)	Pressure Ulcer (n = 12)	Ingrown Nails (n = 5)	Sexual Intercourse (n = 22)	Medical Tests (n = 9)	Pain (n = 13)
Excessive sweating	82%	83%	45%	75%	40%	14%	67%	100%
Irregular heartbeats	65%	56%	32%	50%	20%	5%	44%	92%
Goosebumps	65%	67%	32%	50%	20%	9%	44%	85%
Severe headache	71%	72%	27%	50%	0%	6%	22%	100%

*Percentages calculated by summing “Always,” “Very Often,” “Sometimes,” and “Almost Never” responses included in the questionnaire.

knowing the outcomes of AD (97%), and 2 (3%) respondents stated that AD held no danger to their lives or health. Most respondents (78%) knew how to respond to an episode of AD, whereas 22% did not know. SCI consumers reported that doctors and nurses who specialized in spinal cord medicine were the individuals who had first educated them about AD. Also, they reported that they learned the most from nurses and doctors during their in-patient rehabilitation. When asked if they were able to find information on AD, 47% (28/59) respondents indicated they were able to find information, whereas 46% (27/59) reported they were unable to find information, and 7% (n = 4/59) gave no response.

Personal Experience with AD. Some respondents indicated more than one response for questions on AD symptoms. When asked about their personal experience with AD (Table 1), 37 respondents indicated having a prior episode of AD. Of this subset, 49% (18/37) reported having at least 50 episodes or more of AD since their injury, with 89% (16/18) reporting that the severity and intensity has remained constant. The respondents indicated that the primary triggers for their AD were problems or issues with their bladder (eg, full bladder, bladder tests, infection). The most common symptom of AD was severe headaches (86%), followed by sweating (73%), flushing/blotchy skin (65%), and goose bumps (60%). The least common symptoms and signs reported were seizure (1%) and chest pain (5%).

When asked to rate on a numeric scale (0 = does not affect to 10 = severely affects) how their episodes of AD impacted their quality of life, the average score reported was 6.0 (SD = 2.9). In terms of AD interrupting their activities, approximately 40% of respondents reported AD interfering with work, 44% reported that it interfered with exercise, and 74% stated it impacted on their daily activities (41% of the subset reported being unemployed). Less than 30% said that it interfered with their household chores; 54% of the subset reported that they do not do household chores. The majority reported that they did not go to the hospital to seek treatment for their AD, with 89% managing it by themselves. Finally,

when asked whether their knowledge of AD was adequate, approximately one half the sample (54%) reported that it was adequate, and the majority of the subsample (84%) wanted to know more about AD.

Unrecognized AD. With regards to the subset of 63 respondents (Table 1) who reported never having and/or never hearing of AD, approximately one third of this subset (22/63) reported a variety of AD symptoms exacerbated by urinary bladder or bowel problems and with bowel routine (eg, digital stimulation, inserting suppositories, enema) or medical procedures (eg, cytoscopy) (Table 2). Although 68% of this subset did not know their actual BP, 19% reported that they knew their BP was high, and 29% reported their BP as being low. The majority of participants (60%) only measured their BP when they were not feeling well or when they visited their physician.

Impairment, Level of Education, and AD Knowledge

With regard to knowing about AD (know vs do not know), there was a significant difference between persons with tetraplegia and paraplegia (χ^2 [1, N = 100] = 4.802, $P < 0.05$). Specifically, persons with tetraplegia were more likely to know about AD than persons with paraplegia (Figure 2). As well, there was a significant difference between persons with traumatic etiologies and persons with nontraumatic etiologies (χ^2 [1, N = 100] = 15.341, $P < 0.001$). Persons with traumatic etiologies were more likely to have heard of AD than were persons with nontraumatic etiologies (Figure 3). There was no significant association with knowing about AD with completeness or level of education (<postsecondary vs >postsecondary). In terms of BP knowledge (know BP vs do not know BP); there were no significant associations with level of injury, completeness, etiology, or level of education.

To examine key knowledge issues of AD, persons who had never heard of AD (n = 41) were excluded from the analysis because they were asked not to respond on the sections assessing AD level of knowledge. Among the

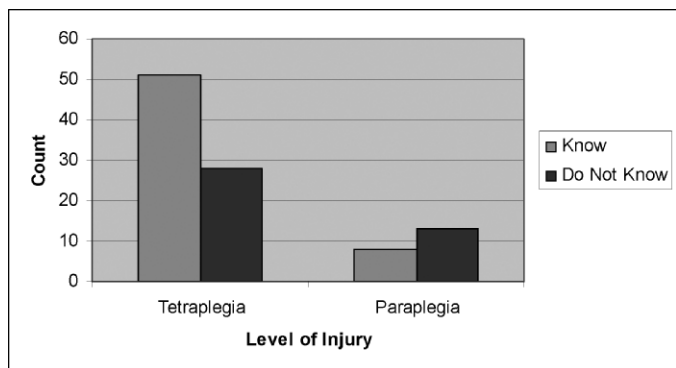


Figure 2. Knowledge of AD as a function of level of injury.

remaining subset of participants ($n = 59$), there were no significant associations on defining AD (correct vs incorrect) with level of injury, completeness, etiology, or level of education. Similarly, there were no significant associations on knowledge of treating AD with level of injury, completeness, etiology (Fisher exact test reported), or level of education. However, knowledge of BP was significantly associated with knowledge of treating AD (Fisher exact test reported; $P = 0.025$). The 34 consumers with SCI who knew their BP knew how to treat their AD, whereas the 12 SCI consumers who knew their BP and the 3 who did not know it reported not knowing how to treat their AD.

Timing and Value of Education for Consumers With SCI

When asked about the value of education on different aspects of AD, almost one half of consumers rated AD education on the questionnaire as “very important” or “important.” Participants indicated the following topics were also of importance: bowel management after SCI (54%), pain management after SCI (53%), and bladder management after SCI (49%). When asked specifically about AD, respondents felt that triggers (45%), symptoms and signs (45%), and treatment (47%) were very important to learn about. However, 15% felt that learning about AD (mechanisms, treatment, symptoms, and signs) was not important.

Family Members

Of the 100 participants, 56 were successfully contacted, and 23 gave consent to mail a questionnaire to a member of their family. A 70% response rate was achieved, with 16 family members responding to the questionnaire (63% were women and 38% were men). The respondents were the spouses/partners (76%) and parents (12%) of consumers with SCI. One was a consumer’s son and the other was a sibling. The majority of the sample (75%) had been caring for their relative after the SCI for more than 3 years, and 25% had been caring for them from 1 to 3 years.

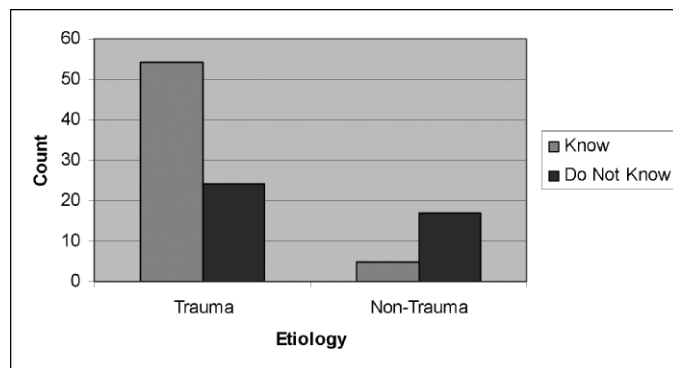


Figure 3. Knowledge of AD as a function of SCI etiology.

AD Knowledge Among Family Members

When asked whether they were able to locate information on AD, the majority of family members (69%) were able to find some information. When asked to describe AD in their own words, some family members described it as follows:

- “Body’s reaction to pain or discomfort that person doesn’t feel due to SCI; feels like needles poking, sweating, headache, BP rises, and sometimes more spasms.”
- “BP rises rapidly to dangerous levels; caused by external stimulus such as pinched flesh.”
- “Rise in blood pressure; feel flushed and can pass out; body’s way of indicating bad sore or full bladder, when can’t be felt.”
- “It is the effect that spinal cord compression has on the body and how it functions.”
- “Urine backs up into kidneys. Renal dysfunction. Headache, flushed face, fever, bladder infection.”

Overall, family members had some knowledge on either the cause and/or symptoms of AD.

Timing and Value of Education for Family Members

Family members indicated that physicians (50%), nurses (19%), or SCI medical professionals (19%) were the best individuals to provide information on AD. However, 19% reported that either a family member with SCI (19%) or another individual with SCI (6%) as the best source. Family members indicated the best source for obtaining information on AD was an interactive CD-ROM (38%), internet web site (38%), group education session (25%), or pamphlets/brochures (25%). Very few reported a video (6%) or audiotape (6%) as the best source.

All participants (100%) reported that learning about symptoms and signs of AD, factors that may trigger episodes of AD, bladder management, and bowel management was very important or important. As well, family members felt that treatment for episodes of AD (94%), BP management (94%), and mechanisms in-

volved in AD (94%) were either very important or important.

In general, family members reported that consumers and their family members should learn about AD and related health management (eg, bladder, bowel, pain) during the period of early rehabilitation and not in the community.

DISCUSSION

The purpose of this study was to evaluate knowledge of AD among consumers with SCI and their family members and to identify the preferred format and timing of education on AD for these stakeholders. In general, there are some clear indicators that consumers with SCI have gaps in their knowledge about AD. Although the sample was a high-risk group for AD, 41% of the sample had never heard of the condition. More concerning was that some responses from consumers indicated they may be having unrecognized episodes of AD. Of the 100 respondents, 22 consumers were identified as possibly having unrecognized episodes of AD. Although a relatively small proportion (22%), this finding is concerning given the potentially devastating consequences AD holds for a person with SCI. It is also possible some respondents from the larger sample who reported not having episodes of AD may be experiencing cases of "silent dysreflexia," which are elevations in BP without overt symptoms (ie, sweating, face flushed). There is evidence highlighting that silent dysreflexia is common during bowel (33) and bladder routines (34) in persons with injuries T6 and above. Given our findings, along with those in the literature on asymptomatic AD, there is a clear need for better education strategies on this serious health complication.

A more definitive answer could be achieved on determining who may be experiencing silent dysreflexia if more respondents' in the consumer group measured their normal BP on a regular basis. Most consumers were unaware of their normal BP when lying down or seated. One recommendation is to encourage patients with SCI to obtain and use BP cuffs to monitor their BP on a more regular basis. This may also serve as a preventative practice considering the cardiovascular and cerebrovascular implications of repeated AD episodes in an aging SCI population (37).

When examining different factors that may affect learning about AD, persons with paraplegia were significantly less likely to know about AD than those with tetraplegia. This finding is not surprising given that AD is 3 times more prevalent in persons with tetraplegia with a complete injury than in those with an incomplete one (9). As a result, information on AD may be promoted less in persons with lower levels of injury. Similarly, persons with nontraumatic etiologies were also less likely to know about AD. Although the number of persons with nontraumatic SCI being admitted to rehabilitation hospitals is growing and episodes of AD have been reported

previously in this population (38), the knowledge on secondary complications associated with nontraumatic etiologies is not well described (39). As well, there is some evidence of AD being less likely to occur in this population (39), which may influence the decision of health professionals to discuss AD with their patients.

Persons who were older were also significantly less likely to have heard about AD than persons who were younger. Because there were no significant differences in years postinjury between these groups, it may be that older adults have different learning styles than younger adults, which may need to be taken into consideration. A challenge of adult education is that it requires building on the prior knowledge and learning experiences of adults, using methods that treat learners with respect while recognizing that people have different styles of learning (40).

Findings from this study also suggest that knowledge regarding BP management is an important factor for monitoring AD. The results indicated people who were more knowledgeable about their BP were more likely to know how to manage their AD than those who did not. Based on these findings, it may be prudent to actively promote BP knowledge or provide sources of information on AD to at-risk persons with paraplegia and nontraumatic etiologies and to perhaps evaluate the learning styles of older adults with SCI.

The consumers who reported knowing about or having AD had a good level of knowledge about recognizing AD symptoms, triggers, treatment, and were aware that the syndrome is potentially life threatening. Similarly, family members also seemed to be able to recognize the signs and symptoms of AD. Although most consumers and their family members reported learning about AD during rehabilitation, there is also a need to offer additional educational resources in the community. Almost 52% of the consumers and 65% of family members indicated they would like to learn more about secondary health complications and that learning about these topics would be best achieved through consultation with a health professional. Some barriers would need to be addressed. For instance, mobility issues for consumers and time constraints often reported by health professionals make it difficult to facilitate this type of learning format once persons with SCI are living in the community.

Despite not fully favoring technology (ie, Internet, CD-ROMs), one solution might be to create a web site where health professionals and consumers can obtain information from one another. There is evidence that Internet access is high for persons with SCI (36), but further work is needed on determining how the Internet may benefit persons with SCI and what role, if any, health professionals may play in helping this population maximize health (41). Further work should also be examined with current activities related to the use of telehealth for those without Internet access (32).

With regard to in-patient rehabilitation, a possible suggestion is to emphasize AD more in the acute period of rehabilitation and in educational sessions on health management and secondary complications (ie, bowel and bladder care, pressure ulcers) to ensure that it is not overlooked or inadvertently missed. Adopting strategies to promote knowledge on AD early in rehabilitation is paramount given the rise in cardiovascular disease in persons with SCI (27,28), along with the fact that pressure ulcers, proper bowel and bladder routines, and pain may all contribute to triggering episodes in persons at high risk for AD. Ensuring that important knowledge about this life-threatening condition is well communicated might help patients to identify and eliminate their specific triggers, which in turn would help them to manage and prevent episodes of AD (7,23,31). It would also be useful to repeat information on AD to patients at follow-up appointments after being discharged from rehabilitation.

Despite being the first study to assess consumer knowledge of AD, several limitations are associated with this study. First, the aims of the study were to describe the current level of AD awareness and knowledge in former patients of a SCI rehabilitation hospital. As a result, a mail survey design was used in an attempt to achieve a large sample size. Similar to other studies using a mail survey design, there are issues with nonresponse bias. Furthermore, not all of the surveys returned were completely filled out, which may be because of the administrative burden for consumers and/or because the consumer did not understand some of the questions. Although the sample obtained is fairly representative of the SCI population, only 11% were under the age of 30 years. There may be significant differences in learning styles and/or health management practices between younger adults with SCI and older adults with SCI.

Another limitation of the study was that the questionnaires used to collect information on AD knowledge are not standardized tools. These questionnaires were developed by experts on SCI and AD and piloted on consumers with SCI, but further work is still needed to evaluate their validity and reliability. As noted above, there may have been some issues with administrative burden for consumers. The family member questionnaire was much shorter than the consumer version but only captured a basic description of AD knowledge. Furthermore, the surveys require refinement to allow for clearer comparisons across groups on knowledge of AD. For example, some questions could be restructured to obtain a quantitative score on AD knowledge, with higher scores reflecting greater knowledge. Future work will focus on improving the current format and design of the questionnaires for SCI consumers and their family members.

Finally, the identification of the 22 persons who may be having unrecognized episodes of AD is speculative given that these evaluations were derived from self-report

responses. A face-to-face clinical interview with examination and 24-hour ambulatory BP monitoring would be a far more accurate means of determining if unrecognized episodes of AD are occurring in these individuals. A tool that potentially renders more false positives may prompt some consumers to pay more attention to their autonomic function and AD risk.

CONCLUSION

In summary, this study highlighted the need to promote knowledge regarding AD to relevant stakeholders. There is a need to identify effective strategies for translating knowledge about AD and to ensure that these strategies are effective for persons of different ages and with different learning styles. Early recognition and prompt treatment of this life-threatening, but easily recognized condition is imperative to minimize effects on a patient's health status. In turn, the prevention and effective management of AD may ultimately reduce the risk of cardiac and cerebrovascular death in this population.

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REFERENCES

1. Noreau L, Proulx P, Gagnon L, Drolet M, Laramée MT. Secondary impairments after spinal cord injury: a population-based study. *Am J Phys Med Rehabil*. 2000;79:526–535.
2. Bloemen-Vrencken JH, Post MW, Hendriks JM, De Reus EC, De Witte LP. Health problems of persons with spinal cord injury living in the Netherlands. *Disabil Rehabil*. 2005;27:1381–1389.
3. Karlsson A. Autonomic dysreflexia. *Spinal Cord*. 1999;37:383–391.
4. Krassioukov AV, Furlan JC, Fehlings MG. Autonomic dysreflexia in acute spinal cord injury: an under-recognized clinical entity. *J Neurotrauma*. 2003;20:707–716.
5. Elliott S, Krassioukov AV. Malignant autonomic dysreflexia in spinal cord injured men. *Spinal Cord*. 2006;44:386–392.
6. Eltorai I, Kim R, Vulpe M, Kasravi H, Ho W. Fatal cerebral hemorrhage due to autonomic dysreflexia in a tetraplegic patient: case report and review. *Paraplegia*. 1992;30:355–360.
7. Mathias C, Frankel H. Autonomic disturbances in spinal cord lesions. In: Bannister R, Mathias C, eds. *Autonomic Failure: A Textbook of Clinical Disorders of the Autonomic Nervous System*. New York: Oxford University Press; 2002: 839–881.
8. Helkowski WM, Ditunno JF Jr, Boninger M. Autonomic dysreflexia: incidence in persons with neurologically

complete and incomplete tetraplegia. *J Spinal Cord Med.* 2003;26:244–247.

9. Curt A, Nitsche B, Rodic B, Schurch B, Dietz V. Assessment of autonomic dysreflexia in patients with spinal cord injury. *J Neurol Neurosurg Psychiatry.* 1997;62:473–477.
10. Cole TM, Kottke FJ, Olson M, Stradal L, Niederloh J. Alterations of cardiovascular control in high spinal myelomalacia. *Arch Phys Med Rehabil.* 1967;48:359–368.
11. Kursh ED, Freehafer A, Persky L. Complications of autonomic dysreflexia. *J Urol.* 1977;118:70–72.
12. Lindan R, Joiner E, Freehafer AA, Hazel C. Incidence and clinical features of autonomic dysreflexia in patients with spinal cord injury. *Paraplegia.* 1980;18:285–292.
13. Colachis SC 3rd, Clinchot DM. Autonomic hyperreflexia associated with recurrent cardiac arrest: case report. *Spinal Cord.* 1997;35:256–257.
14. Colachis SC, Fugate LP. Autonomic dysreflexia associated with transient aphasia. *Spinal Cord.* 2002;40:142–144.
15. McGregor JA, Meeuwse J. Autonomic hyperreflexia: a mortal danger for spinal cord-damaged women in labor. *Am J Obstet Gynecol.* 1985;151:330–333.
16. Pan SL, Wang YH, Lin HL, Chang CW, Wu TY, Hsieh ET. Intracerebral hemorrhage secondary to autonomic dysreflexia in a young person with incomplete C8 tetraplegia: a case report. *Arch Phys Med Rehabil.* 2005;86:591–593.
17. Valles M, Benito J, Portell E, Vidal J. Cerebral hemorrhage due to autonomic dysreflexia in a spinal cord injury patient. *Spinal Cord.* 2005;43:738–740.
18. Myers J, Lee M, Kiratli J. Cardiovascular disease in spinal cord injury: an overview of prevalence, risk, evaluation, and management. *Am J Phys Med Rehabil.* 2007;86:142–152.
19. Braddom R, Rocco J. Autonomic dysreflexia. A survey of current treatment. *Am J Phys Med Rehabil.* 1991;70:234–341.
20. Erickson R. Autonomic hyperreflexia: pathophysiology and medical management. *Arch Phys Med Rehabil.* 1980;61:431–440.
21. Lee BY, Karmakar MG, Herz BL, Sturgill RA. Autonomic dysreflexia revisited. *J Spinal Cord Med.* 1994;18:75–87.
22. Kewalramani L. Autonomic dysreflexia in traumatic myelopathy. *Am J Phys Med Rehabil.* 1980;59:1–21.
23. Teasell R, Arnold A, Krassioukov A, Delaney G. Cardiovascular consequences of loss of supraspinal control of the sympathetic nervous system following spinal cord injuries. *Arch Phys Med Rehabil.* 2000;81:506–516.
24. Consortium for Spinal Cord Medicine. Acute management of autonomic dysreflexia: adults with spinal cord injury presenting to health-care facilities. *J Spinal Cord Med.* 2002;25:S67–S88.
25. Consortium for Spinal Cord Medicine. Autonomic dysreflexia: what you should know. Available at: <http://www.pva.org/site/DocServer/ADC.pdf?docID=569>. Accessed January 8, 2008.
26. Muldoon D, Mierzwa S, Haider N, Krassioukov A. Autonomic dysreflexia questionnaire for spinal cord injured subjects at Sitrin Medical Rehabilitation Center in Utica NY. *J Neurotrauma.* 2000;17:989.
27. Bauman WA, Raza M, Chayes Z, Machac J. Tomographic thallium-201 myocardial perfusion imaging after intravenous dipyridamole in asymptomatic subjects with quadriplegia. *Arch Phys Med Rehabil.* 1993;74:740–744.
28. Bauman WA, Raza M, Spungen AM, Machac J. Cardiac stress testing with thallium-201 imaging reveals silent ischemia in individuals with paraplegia. *Arch Phys Med Rehabil.* 1994;75:946–950.
29. Krassioukov AV, Furlan J, Fehlings MG. Medical comorbidities, secondary complications, and mortality in elderly with acute spinal cord injury. *J Neurotrauma.* 2003;20:391–399.
30. Tomassoni P, Campagnolo D. Autonomic dysreflexia: one more way EMS can positively affect patient survival. *JEMS.* 2003;28:46–51.
31. Blackmer J. Rehabilitation medicine: autonomic dysreflexia. *CMAJ.* 2003;1:931–935.
32. LaPierre NM, Blackmer J, Coutu-Wakulczyk G, Dehoux E. Autonomic dysreflexia and telehealth. *Can Nurse.* 2006;102:20–25.
33. Kirshblum S, House J, O'Connor K. Silent autonomic dysreflexia during a routine bowel program in persons with traumatic spinal cord injury: a preliminary study. *Arch Phys Med Rehabil.* 2002;83:1774–1776.
34. Linsenmeyer TA, Campagnolo DI, Chou IH. Silent autonomic dysreflexia during voiding in men with spinal cord injuries. *J Urol.* 1996;15:519–522.
35. Eklund MB, Krassioukov AV, McBride KE, Elliott SL. Incidence of autonomic dysreflexia and silent autonomic dysreflexia in men with spinal cord injury undergoing sperm retrieval: implications for clinical practice. *J Spinal Cord Med.* 2008;31:33–39.
36. Edwards L, Krassioukov AV, Fehlings MG. Importance of access to research information among individuals with spinal cord injury: results of an evidenced based questionnaire. *Spinal Cord.* 2002;40:529–535.
37. Groah SL, Weitzenkamp D, Sett P, Soni B, Savic G. The relationship between neurological level of injury and symptomatic cardiovascular disease risk in the aging spinal injured. *Spinal Cord.* 2001;39:310–317.
38. Furlan JC, Fehlings MG, Halliday W, Krassioukov AV. Autonomic dysreflexia associated with intramedullary astrocytoma of the spinal cord. *Lancet Oncol.* 2003;4:574–575.
39. McKinley W, Tewksbury M, Godbout C. Comparison of medical complications following nontraumatic and traumatic spinal cord injury. *J Spinal Cord Med.* 2002;25:88–93.
40. Collins J. Education techniques for lifelong learning. *RadioGraphics.* 2004;24:1483–1489.
41. Drainoni ML, Houlihan B, Williams S, et al. Patterns of internet use by persons with spinal cord injuries and relationship to health-related quality of life. *Arch Phys Med Rehabil.* 2004;85:1872–1879.